

Shifting Gears Summit 2021 Communique

Australasia's first health consumers conference involving over 820 delegates from Australia and around the world has given fresh momentum to consumer direction and influence in health care.

The first ever *Shifting Gears Summit* on consumer experience and leadership in health care was hosted in March 2021 by the Consumers Health Forum of Australia (CHF) – Australia's peak body for health consumers.

Many point to the need for more person-centred care – the [OECD](#), the Australian Productivity Commission in its 2017 [Shifting the Dial](#) Report and the CSIRO's [Future of Health](#) report to mention a few.

In 2018 CHF released a White Paper called [Shifting Gears: Consumers Transforming Health](#) as our contribution to this discussion.

The White Paper set out the transformational policy shifts needed to make the system more person-centred and described the many and varied roles consumers can play in shaping better policy, programs, research and services.

Summit 2021 continued that conversation.

Consumer leaders and experts with an interest in health care consumer affairs covered topics as diverse as why it is time to re-imagine health and social care; 'big ideas' for change; global trends in safety and quality in health care; and future horizons in healthcare.

Six concurrent streams demonstrated the scale and variety of consumer health issues: consumer involvement in research; consumers' role in ensuring value-based health care; consumer leadership; consumer enablement; New Zealand consumer issues and consumer and community engagement in COVID-19.

Now the focus is shifting further from consumer-centred care to consumers as partners in healthcare.

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Consumers of today, partners of tomorrow

Central messages included:

- No longer weighed down with health information, lacking support to understand their choices, unaware of how new healthcare technologies will impact their health and only partially involved in the development of healthcare's future; the consumer of tomorrow will be recognised as a full actor of care, own their medical information, understand the value of evidence-based medicine, be better decision makers and be fully engaged as transformational partners.
- Consumers expect a real say in their health care and outcomes are likely to improve where consumer and care providers collaborate as partners in care. The notion of the 'wise' consumer equipped with knowledge and skills to exercise choice and control in their health and care; and the leadership skills to influence and shape policy emerged.
- The consumer is often the only individual in the care setting to have insider experience and knowledge about all aspects of their care. The best health care professionals and organisations should turn to and listen to the lived experience of consumer advocates in improving health policy and practice. Lived experience and consumer insights qualitative data are equally valid to quantitative data in research.
- Day one of the Summit coincided with National Close the Gap Day. There was strong recognition of the need for health systems to embrace the socio-ecological and community-controlled ethos of indigenous healthcare, and a call for strengthening indigenous voices in consumer advocacy and future events. Indigenous consumer rapporteur, Lara Pullin, described her Dark Emu Dreaming – a black emu defined by the stars around it, saying it is the patterns in the darkness surrounding the starlight that is important.
- Organisations need to be 'engagement capable': they must actively create environments where consumer-centred services can flourish. Culture, strategy and practices all need to work in tandem to deliver consumer-centred programs and services. Health services successful in delivering consumer-centred care focus all aspects of their organisation and exhibit several attributes including comprehensive care delivery; a clear purpose, strategy and strong leadership;

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people, capability and a person-centred culture; person centred governance systems and measurement for improvement; and demonstration of consumer/health systems partnerships in healthcare.

- We are at risk of a growing shadow of inequity as a consequence of widening wealth disparities. The development of ever more varied and expensive treatments has increased the risk of the well-off having care not available to others who are often the 'unheard yet most vulnerable'. Health consumer advocates play a vital role in pressing for quality health care to be available to all and for reforms to the system not only to make the most of medical advances but to promote wellness through preventive health measures.

What is needed now?

Several ideas to support the roles consumers can play as agents of change in shaping policy, research, programs and services were generated or reinforced:

- a more structured approach to the development of health consumer leaders, advocates and their organisations as an integral part of the health system through the establishment of an **academy** for research, education and training
- a bespoke **mentoring program** for consumer advocates
- the value of consumer advocates, their insights and advice must be recognised with appropriate **remuneration**
- the appointment of consumer representatives to health, hospital and research entities is now commonplace. While much advice is drawn from this consumer presence, when it comes to the actual decision-making and funding choices, the consumer representative can be excluded. **Leadership and education in collaborative practice** and better ways to work together and share power through leading-edge programs such as CHF's **Collaborative Pairs Australia** is needed
- The necessity of consumer voice and involvement is widely recognised but has meant that growing responsibility is placed on a relatively small number of people who have the wisdom and experience to bring user and carer knowledge to the table and often due so on a volunteer basis. A diverse and **continually refreshed national pool of consumer advocates** supported with opportunities to network, learn, and exchange knowledge is imperative.
- Further development and uptake of **tools to systematically gather and analyse consumer stories and sentiment** are required, specifically re-

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development of *Real People, Real Data* and sustainability of the Australian Health Consumer Sentiment Survey

Immediate priorities for CHF

- **Advocate** for the academy; sustainable funding for *Collaborative Pairs*; a Consumer Mentoring Program; and modernisation of *Real People, Real Data*.
- **Implement** and further adapt *Collaborative Pairs Australia* to continue to equip consumers and providers in various organisational settings to work together effectively.
- **Launch** *Consumer Link* – an initiative to support consumer representatives from across the country to network, learn and exchange information commencing with a launch webinar on 14 April.
- **Continue** to take the pulse on the issues that matter to consumers by repeating the Australian Health Consumer Sentiment Survey first conducted in 2018 and launching a Consumer Report Card on the performance of the health system in Patient Experience Week, 26-30 April.

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